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In The

Supreme Court of the United States

October Term, 1992

EVERETT R. RHOADES, M.D., DIRECTOR OF THE INDIAN HEALTH SERVICE, ET AL.,

Petitioners,

V.

GROVER VIGIL, ET AL.,

Respondents.

On Writ Of Certiorari
To The United States Court Of Appeals
For The Tenth Circuit

BRIEF FOR THE AMICI CURIAE IN SUPPORT OF RESPONDENTS

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Pursuant to Rule 37.3 of the Rules of the Supreme Court of the United States, the Native American Protection & Advocacy Project, Post Office Box 306, Window Rock, Arizona, 86515, and the Navajo Nation, Department of Justice, Post Office Drawer 2010, Window Rock, Arizona, 86515, file the attached brief amici curiae in support of Respondents to the above-captioned case. Both parties have consented in writing to the filing of this brief; said letters of consent accompany this brief as required by Rule 37.3.

INTEREST OF AMICI CURIAE

The Native American Protection & Advocacy Project (NAPAP), a project within DNA-People's Legal Services, Inc., provides free legal assistance to individuals with physical and mental disabilities residing on the Navajo Nation and the Hopi Reservation; or are members of the San Juan Southern Paiute Tribe; the service area of NAPAP extends into the States of Arizona, New Mexico, and Utah. NAPAP advocates on behalf of individuals with disabilities in Tribal, State and Federal forums. Several of NAPAP's current clients are Native American children with disabilities who are having problems with the provision of services.

The Navajo Nation is the largest Indian tribe in the United States, having nearly one-quarter of a million members. The Nation covers 25,000 square miles and extends into the states of Arizona, New Mexico and Utah. A large segment of the Nation's members are children, and a significant portion of those children have

disabilities and are eligible for ICP services. The Navajo Nation represents the interests of its children in this Brief.

Amici Curiae are concerned about the potential impact an adverse decision in this case will have on Native American children with disabilities in general, and Navajo children with disabilities in particular, in light of the lack of services available to Native American children with disabilities nationwide and here within the Navajo Nation. Allowing the Bureau of Indian Affairs and the Indian Health Service to terminate the Indian Children's Program (ICP) without notice and an opportunity to comment would seriously affect the ability of Native American children to obtain the health services necessary for assistance in becoming healthy participants in society.

SUMMARY OF ARGUMENT

Native Americans suffer from disabling conditions at a rate much higher than the general population, and thus are in need of appropriate services at a level much higher than the general population. Native Americans residing on a reservation tend to face additional barriers to the provision of these services which prevents many Native Americans from receiving appropriate services. The ICP has been able to remove some of these barriers to the receipt of such services by Native American children in this area, and has proven to be an invaluable service for these children. Termination of the ICP without the kind of full consideration that would result from notice and comment will result in irreparable harm to many Native American children with disabilities.

ARGUMENT

I. NATIVE AMERICANS AND NAVAJOS SUFFER FROM DISABILITIES AT A RATE SIGNIFICANTLY HIGHER THAN THE GENERAL UNITED STATES POPULATION AND THEREFORE HAVE AN INCREASED NEED FOR APPROPRIATE SERVICES

A. The General Native American Population

In 1990 there were approximately 1.9 million Native Americans, Eskimos and Aleuts in the United States. 1990 Census, RESIDENT POPULATION BY STATE AND BY RACE: 1990. There are 278 Indian reservations, and approximately 24 percent of the Native Americans reside in those reservations. Administration for Native Americans (ANA), NATIVE AMERICAN DATA BASES (September 10-13, 1992), pp. 2-3. The on-reservation Native American population is much younger than the general population. Nearly half of the on-reservation families with children had incomes near or below the poverty level in 1979. ANA, at pp. 2-3. Nearly half of the Native American population is concentrated in the states of Arizona, California, New Mexico, Oklahoma and Washington. 1990 Census. And although Native Americans comprise only one percent of the total United States population, they comprise 50 percent of the diversity in the United States. ANA, at p. 1.

The National Congress of American Indians (NCAI) has found that Native American infants are being born with disabling conditions at three times the rate of all other babies born in the United States; Native American men have a seven times greater chance of becoming disabled before their 26th birthday than any other group of

men in the United States; research has indicated that nearly eighty-five percent of all the disabilities prevalent among Native Americans can be prevented or rehabilitated; state prevention and rehabilitation services seldom reach urban Indians and almost never cross reservation boundaries; and, with the exception of some Tribal Vocational Rehabilitation Programs, there are no services on Indian reservations specifically tailored to address the needs of disabled Native Americans. National Congress of American Indians, RESOLUTION TO CREATE A COMMITTEE ON DISABILITIES (November 1990).

The Native American Research and Training Center (NARTC) has reached the following conclusions: Native Americans have the second greatest number of persons with disabling conditions of all ethnic groups in the United States; Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE) are found in Indian infants nationally at the rate of 30% and the rate is increasing annually at 6%; for every child born with FAS, it is estimated that there are three others who have FAE; visual impairments occur three times more frequently among Native Americans, and hearing losses four times more frequently, than among the general population; and bacterial meningitis, otitis media, accidents and trauma, and congenital anomalies occur among Indian populations at an overall rate of twice the national average. Factors that contribute to bacterial meningitis include chronic otitis media and the absence of running water and sanitation facilities in many on-reservation Native American communities.

Additionally, Native Americans had the highest birth rate in 1986, almost double the overall United States birth rate. A.N.A., at p. 7. Native American children ages three through 21 exhibit a much higher prevalence of learning disabilities and multi-handicapping conditions (11.86 percent) than the corresponding population at large (1.81 percent). J. Toubbeh, Ph.D., HANDICAPPING AND DIS-ABLING CONDITIONS IN NATIVE AMERICAN POPU-LATIONS, p. 4. A 1989 investigation by the United States General Accounting Office (GAO) revealed that for Native American preschool children, who had Individual Education Programs completed or some diagnostic evaluation reports in their school records, the primary diagnosed handicapping conditions were: speech impaired; developmentally delayed; multihandicapped; other health impaired; specific learning disability; and mentally retarded. United States General Accounting Office, SPE-CIAL EDUCATION: ESTIMATES OF HANDICAPPED INDIAN PRESCHOOLERS AND SUFFICIENCY OF SER-VICES (March 1990), pp. 46-47. Some of the main causes of disabling conditions in Native American children include congenital abnormalities, accidents, infections (such as meningitis), and developmental delays caused by poor or inadequate nutrition. J. Joe and C. Locust, GOVERN-MENT POLICIES AND THE DISABLED IN AMERICAN INDIAN COMMUNITIES (Update August 1989), p.1.

These alarming statistics indicate that many Native Americans suffer from one or more disabling conditions, thus creating a special need for services appropriate for individuals with disabilities. Those Native Americans who are located near metropolitan areas are sometimes able to take advantage of the multitude of services available in those areas, but Native Americans who remain on their reservation have only very limited federal programs to turn to for help. Because the on-reservation population is very young, the need for appropriate services for Native American children with disabilities is particularly compelling.

B. The Navajo Reservation Population

The Navajo Nation with its geographic and population size has a median age of 21.8 years, and the 1990 Census shows that Navajos 17 years of age and younger residing on the reservation constitute 43.5 percent of the total 1990 population. Sixty percent of Navajo children under five years of age are living below the poverty level; for Navajo children ages six to eleven the rate is 57 percent. The overall rate of Navajos living below poverty level is 54 percent. The unemployment rate on the Navajo Nation is 27.9 percent.

Although the number of developmentally disabled Navajos has been estimated to be between 9,000 and 13,500 persons, only 3,000 have been identified and are receiving services – less than 21 percent. F. Hodge and S. Weinmann, DISABLED AMERICAN INDIANS; AN OVERVIEW OF THE ETIOLOGY OF "ISABILITY IN THE ALASKA, MONTANA AND NAVAJO AREAS, 1987, p. 16. It has also been estimated that three percent of Navajo newborns have a developmental disability. *Id.* A survey conducted in 1987 found that there were 7,355 Navajos with disabilities between the ages of five and twenty-one, representing 11.33 percent of the overall Navajo school

population. N.E.E.D.S. Research Project, NAVAJO EVAL-UATION OF EXISTING DISABILITY SERVICES RESEARCH PROJECT (1987), p. 71.

The ten most frequent disabling conditions found in Navajo children by the IHS include: developmental delay; seizure disorder; language/speech delay; meningitis; prematurity; cerebral palsy; mental retardation; FAS/FAE; spastic quadriplegia; and failure to thrive. F. Hodge, at p. 9a.

Thus the primary disabling conditions among Navajo children mirror those found among the Native American population in general. The causes of these disabling conditions can be related to four major sources found on the Navajo Nation, including low birth weight, bacterial meningitis, FAS/FAE, and otitis media. F. Hodge, at pp. 10-12, 17.

Many Navajo women become mothers during their teen years which puts their children at risk for low birth weight. Low birth weight has been considered a related factor in many disabling conditions, including developmental delay, language and speech delay, cerebral palsy and mental retardation. F. Hodge at p. 10.

Additionally, the incidence of bacterial meningitis is a significant problem on the Navajo Reservation, and in 1987 was the major cause of death among Navajo infants and young children. Bacterial meningitis has been related to problems of developmental delay, seizure disorder, orthopedic disorders, language delay and mental retardation. Bacterial meningitis comparisons show a rate of 27.7 per 100,000 Navajos from 1968 to 1973 to a rate of 5.9 per

100,000 in Bernalillo County, New Mexico from 1964 to 1971. F. Hodge, at p. 10-11.

FAS has been considered a likely major cause of serious health problems among the Navajo. FAS and FAE have been associated with developmental delay, seizures, orthopedic problems, cerebral palsy and mental retardation. F. Hodge, at p. 11.

Otitis media, which is an infection of the middle ear, has been found to be extremely prevalent, infecting approximately 4.2 percent of Navajo children. This infection, even when it does not cause partial or complete deafness, profoundly affects the psychological and social development of these children. F. Hodge, at p. 17.

Children are our most important asset, and children with disabilities especially require our utmost attention. The statistics indicate a desperate need for appropriate services for handicapped children on the Navajo Nation.

II. THERE ARE SIGNIFICANT BARRIERS TO ACCESS OF DISABILITY RELATED SERVICES FOR NATIVE AMERICANS AND NAVAJOS RESIDING WITHIN THE RESERVATIONS

The availability of disability-related services on reservations throughout the United States is a critical problem. The relative remoteness, isolation and economic characteristics of Indian reservations present extreme difficulties in recruitment and retention of qualified health care professionals. In June 1984, 547 special education positions went vacant in New Mexico. N.E.E.D.S. Research Project, at p. 31. A 1990 survey of the BIA's

Branch of Exceptional Education revealed that many disabled Native American preschoolers received inadequate services, primarily due to the lack of qualified service providers on or near Indian reservations, compounded by the lack of funding to hire them even if they were available. GAO Briefing Report to Congressional Requesters, SPECIAL EDUCATION: ESTIMATES OF HANDICAPPED INDIAN PRESCHOOLERS AND SUFFICIENCY OF SERVICES (1990), p. 29.

Indeed, even when on-reservation services are available, inter-agency disagreements create a bureaucratic nightmare. The United States Department of Education and the United States Department of Interior (Interior) dispute who has responsibility for Education of the Handicapped Act (EHA) services. In 1990, when it reviewed the GAO's draft report, Interior reported:

- "1) in receiving EHA funds, it agreed to assure services to those children enrolled in its programs;
- 2) if no other agencies will provide services to handicapped Indian children enrolled in non-BIA programs, BIA may do so; and
- 3) the education delivery system on Indian reservations is too complex to specify, exclusively and without exception, which agency is responsible for providing special education services to handicapped Indian preschoolers on reservations with BIA schools."

GAO Briefing Report, at p. 33. (emphasis added). The United States Department of Education contends that

once the Interior receives EHA funds it has the responsibility to provide EHA mandated services to all reservation Indian children on those reservations with BIA schools, regardless of the program they are enrolled in and regardless of the bureaucratic complexity found on the reservation. Id.

The GAO and the BIA identified three factors as barriers to the provision of appropriate services on reservations: 1) lack of qualified personnel; 2) lack of funding; and 3) the uncertainty of appropriate agency responsibility. Each of these three factors exist on the Navajo Nation; additional factors also appear.

The Indian Health Service (IHS) is the primary provider of health services on the Navajo Nation. However, given the size and terrain of the Nation these services are not easily accessible to Navajos. In many parts of the Nation a visit to IHS requires travel over a long distance on rough and sometimes impassable roads. Once there, a Navajo needing assistance faces a long wait at the facility, IHS eligibility requirements, and all too frequently, the absence of any specialty services. If the Navajo requires a health service unavailable at the local facility, he or she must travel to Albuquerque or Phoenix for treatment at these more extensive facilities, provided that IHS is willing to make a referral.

A survey of Navajo families disclosed their opinion that the second most important area needed in helping Navajos with disabilities was special education (appropriate housing was named the most important). N.E.E.D.S. Research Project, at p. 57. The survey also revealed the need to coordinate services among all providers. Id at p. 72, 75.

Other barriers to obtaining services include cultural lifestyles, economic conditions and the highly rural nature of life on the Navajo Nation. Many of the Nation's residents speak only Navajo, many elders speak very little English, and many follow traditional beliefs. Some Navajos see western medical practices as in conflict with Navajo tradition. The high unemployment rate and number of individuals living below poverty level dictate substantial dependence on the public health services.

III. THE ICP PROVIDES AN INVALUABLE RESOURCE FOR NAVAJOS AND MANY NATIVE AMERICAN CHILDREN WILL BE INJURED IF THE ICP IS ALLOWED TO BE TERMINATED

The Indian Children's Program (ICP) helps overcome many of the barriers discussed in this Brief. The Program is designed to provide diagnostic and assessment services to Native American children in this area in order to determine the cause and nature of health and education problems, and to provide assistance to families to maximize the utilization of health resources available in the community. The Program has made a commitment to match children with appropriate services, enhancing the number of quality services available. Where necessary, it provides additional services, training, and consultation to better meet the needs of children and their families.

The ICP is located through the offices of Northern Arizona University, University of Utah and University of New Mexico, and has an on-site office. The ICP has hired Native Americans who can assist in providing culturally specific services. ICP personnel travel to the clients' residences to provide services. The locations of the ICP enable it to hire qualified personnel through the universities. The ICP also acts as a watchdog to ensure that responsible agencies provide legally mandated services, catching those children who fall between the cracks and are ineligible for other services. The ICP provides essential training and educational programs to organizations involved with Indian children.

Currently the ICP has 345 clients, almost half of whom are Navajo. The majority of ICP clients have been identified as learning disabled, emotionally disturbed, mentally retarded, cerebral palsied, communications disordered or multihandicapped. By definition, these 345 clients are Native American children ineligible for services elsewhere, and if the ICP were terminated they would be left without alternate services.

The ICP is an essential program for Native American children with disabilities in this area; it removes many of the barriers existent in the provision of appropriate services. Termination of the ICP will result in many disabled Native American children not receiving appropriate and needed services. Providing services to children with disabilities at the earliest age possible is essential to the rehabilitation and prevention of disabling conditions.

CONCLUSION

For the foregoing reasons the decision of the Tenth Circuit Court of Appeals should be affirmed.

Respectfully sumitted,

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